Development of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)

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Abstract

Introduction

Do-not-attempt-cardiopulmonary-resuscitation (DNACPR) practice has been shown to be variable and sub-optimal. This paper describes the development of the Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). ReSPECT is a process which encourages shared understanding of a patient's condition and what outcomes they value and fear, before recording clinical recommendations about cardiopulmonary-resuscitation (CPR) within a broader plan for emergency care and treatment.

Methods

ReSPECT was developed iteratively, with integral stakeholder engagement, informed by the Knowledge-to-Action cycle. Mixed methods included: synthesis of existing literature; a national online consultation exercise; cognitive interviews with users; a patient-public involvement (PPI) workshop and a usability pilot, to ensure acceptability by both patients and professionals.

Results

The majority (89%) of consultation respondents supported the concept of emergency care and treatment plans. Key features identified in the evaluation and incorporated into ReSPECT were: The importance of discussions between patient and clinician to inform realistic treatment preferences and clarity in the resulting recommendations recorded by the clinician on the form. The process is compliant with UK mental capacity laws. Documentation should be recognised across all health and care settings. There should be opportunity for timely review based on individual need.

Conclusion

ReSPECT is designed to facilitate discussions about a person's preferences to inform emergency care and treatment plans (including CPR) for use across all health and care settings. It has been developed iteratively with a range of stakeholders. Further research will be needed to assess the influence of ReSPECT on patient-centred decisions, experience and health outcomes.

Introduction

Do-not-attempt-cardiopulmonary-resuscitation (DNACPR) decisions have been used since the 1970s.[1] Variations and sub-optimal practice across healthcare settings have been identified when considering, discussing, and documenting anticipatory decisions about CPR.[2-4] DNACPR decisions were sometimes wrongly interpreted, leading to withholding of other aspects of care.[2,5-7] Documentation recording CPR decisions was often institution-specific, meaning decisions were not transferrable between organisations involved in a person's care.[8,9]

An alternative to stand-alone DNACPR decisions is the use of plans made in advance which contextualise recommendations about CPR within recommendations for a person's broader emergency care and treatment.[10,11] There is evidence that clinicians welcome this approach; that it promotes better recording of patient preferences,[12,13] and can reduce patient harm when compared to a simple DNACPR system.[6] An emergency care and treatment plan can complement a broader advance care plan (ACP). It provides a succinct summary of patient preferences and realistic treatment recommendations to guide those needing to make immediate decisions in an emergency and when loss of capacity may prevent patient involvement.

In October 2014 patients, clinicians, health service commissioners and regulators attended a summit at the Royal Society of Medicine on DNACPR decisions in the UK. The meeting heard findings about variation and sub-optimal practice in relation to DNACPR across healthcare settings, alongside exemplars of best practice. Contextualising 'decisions' about CPR (including 'for CPR' recommendations) within a nationally recognised, broader plan for emergency care and treatment was identified as a key priority to improve quality of care.[2]

In response, the Resuscitation Council UK, in partnership with the Royal College of Nursing, clinical and patient and public stakeholders including representation from all 4 nations of the UK, established a Working Group, to develop a new, standardised approach to discussing and recording recommendations about CPR in the context of broader emergency plans (box 1). This paper describes the early development and the evaluation of **Re**commended **S**ummary **P**lan for **E**mergency **C**are and **T**reatment (ReSPECT) to the point where it was useable by clinicians and was ready for implementation in practice with ongoing monitoring and evaluation.

[Insert box 1]

Methods

The aim was to develop an Emergency Care and Treatment Plan (ECTP) as an alternative to an approach that focused solely on withholding CPR.

Key objectives were:

- to bring together published evidence and clinical experience;

- to develop an approach with, and acceptable to, clinicians, patients, carers and other members of the public;
- that the output should be used across all health and care settings;
- to contextualise a decision/recommendation about CPR within overall goals of care;
- to focus on care and treatments to be given as well as those that are not wanted or that would not work.

An ECTP was developed and revised iteratively by integrating the Knowledge to Action (KTA) cycle[14] with a mixed methods approach to evaluation until it was agreed to be acceptable for use in clinical practice by experienced clinicians in general practice or any clinical speciality for completion with patients or their representatives at any point in the patient's care. The KTA cycle is a framework which conceptualises the dynamic, complex nature of translating knowledge into practice, incorporating ongoing evaluation. Embedded stakeholder engagement throughout was integral to the development and subsequent adoption.[15, 16]

Phase 1: Development of a prototype ECTP

Published literature and existing approaches to emergency care and treatment planning in the National Health Service (NHS) were reviewed.[6,11-13,17] Common and contrasting elements of existing approaches were synthesised. A modified Delphi approach was used to iteratively develop a prototype ECTP, integrating patients' and members of the public's perspectives with those of health professionals from multiple specialities and settings. Supporting documents and resources, including education materials, were developed.

Phase 2: Consultation survey and cognitive interviews

A survey consultation was developed to determine opinions on the generic concept of an ECTP, alongside views of and comments on the prototype ECTP form, designed to "nudge" clinicians and patients into a process which respected both patient preferences and clinical judgement, and supporting information materials. ***As a consultation exercise we expected responses from interested parties rather than a representative sample of the UK population***. Open questions inviting free-text responses, and questions requiring selection of one or more predetermined responses were included. The survey was pilot tested by members of the Working Group and refined to improve clarity.

The survey was administered online (SurveyMonkey, Dublin), with paper copies available on request. Patients and other members of the public, health and care professionals, provider organisations, regulatory bodies and any others who registered an interest were invited by email to participate and cascade information to others (See supplementary table 1).

Binary and categorical response questions were analysed using descriptive statistics. One researcher (CH) summarised and categorised free-text comments into themes. A second researcher (GDP) tested them against the data for plausibility. Both researchers agreed the final overarching themes.

A purposive sample (i.e. a non-probability sample selected to cover a variety of characteristics of those who would use an ECTP) of interview participants were identified through the Working

Group's networks to gain a range of views and experiences. Those who agreed to take part were sent the ETCP documents ahead of individual cognitive telephone interviews. A method of interviewing to understand the ways respondents process and respond to what is written, to assess whether their understanding was consistent with the intent of the developers. 2 members of the public, 2 paramedics, 3 senior nurses (nursing home senior nurse, community matron, palliative care specialist), 2 paediatricians, 2 physicians (acute and palliative care), a general practitioner (GP) and a surgeon were interviewed by CH.

Clinicians were asked to 'think aloud' as they worked through how they would use the ECTP with a patient.[18] The sections were designed to guide or prompt the clinician about all the different elements necessary to having a conversation to plan for an emergency. This approach allowed identification of sections that worked well and those that were problematic. Members of the public were asked to think aloud about how they would use the form to plan future care recommendations with their own doctor or a relative's doctor. Paramedics, (who would rarely if ever complete a plan, but would have to use the ECTP in an emergency situation), were given 2 emergency scenarios. They were asked to think through what they would do and asked to identify potential areas of confusion and make suggestions for improvement.

Comments from participants' interviews were summarised and categorised by content and process (comprehension, retrieval, decision and response processes).[19] Consistency with or variation from the original intent were assessed using a framework covering each section of the ECTP recorded on the form.[20] Any consistent misunderstandings, sections that did not work as intended, or other problems were identified. Views of the associated guidance documents were summarised and categorised by topic according to their relevance for clarity, usefulness in relation to recording discussions and the plan of care using the form or missing information that would improve the guidance. Suggestions for improvements were collated and changes were made to the ECTP form and supporting documents to address the identified issues.

The working title (ETCP) was replaced with "Recommended Summary Plan for Emergency Care and Treatment (ReSPECT)" New documents incorporated the key changes resulting from the consultation, with design by HELIX, a joint enterprise between Imperial College London and the Royal College of Art.

Figure 1 shows the iterative development of the ECTP/ReSPECT form

[Insert figure 1]

Phase 3: Patient and public focus groups

Patient and public feedback was sought from members of the National Institute for Health Research (NIHR) Wessex Collaboration for Leadership in Applied Health Research and Care (CLAHRC) patient-and-public-involvement group. The group was run as a workshop, supported by trained CLAHRC facilitators. Participants worked through the ReSPECT documents (a poster and flyer to raise awareness of the ReSPECT process, the form to record recommended care and treatment in emergency situations, and the patient information sheet). Overall key messages to feed back to the Working Group were agreed.

Phase 4: Usability pilot

Clinicians at four sites (Scotland, Northern England, the English Midlands and London) pilot tested ReSPECT with approximately 10 patients each. Sites covered paediatric intensive care, paediatric palliative care in acute and community settings, nursing home, adult hospice, community and acute palliative care, and adult acute medical admissions. In larger settings the pilot was limited to particular departments (e.g. acute hospital wards). A principle investigator at each site organised the intervention and recruited focus group participants.

Clinician's participated in focus groups. A logic model (figure 2) of how the ReSPECT process and associated materials were intended to work informed interview topics, focusing on pilot aims:

- assessment of usability in clinical practice,
- suitability and understandability of the ReSPECT process, using the form to record care and treatment recommendations and associated guidance
- identification of usability improvements needed.

A researcher CH led five focus groups supported by JS at one site and another researcher GD at the others. Interviews were audio recorded and transcribed for analysis.

[Insert figure 2]

Focus group transcripts were analysed using Framework analysis.[21] A thematic framework was developed, using the pilot aims and the logic model. Transcripts were inductively coded and categorised independently by the 2 researchers (CH and GD). Categories were assessed for fit with the framework themes, and additional themes were added where necessary. The two researchers discussed and agreed the final categories and the final themes.

Governance approvals

Local approvals for service development projects were obtained at each site.

A summary of the overall development and evaluation framework is presented in figure 3.

[Insert figure 3]

Results

Phase 1: Development of a prototype emergency care and treatment plan

Between 12-20% of UK acute hospitals and community services had introduced some style of ECTP that had either replaced or sat alongside a DNACPR approach and form.[6,12,24] A range of other protocols and supporting documentation was examined to identify core themes from existing ECTP systems to inform the prototype ECTP. These systems included: Physician Orders for Life Sustaining Treatment (POLST, USA),[22] Medical Orders for Scope of Treatment (MOST, Canada),[23] Universal Form of Treatment Options (UFTO, Cambridge, UK),[10] Treatment Escalation Plans (TEPs, Devon, UK), Unwell and Potentially Deteriorating Patient Plan (UP, Gloucester, UK), Deciding Right (North East England).

Phase 2: Consultation survey and cognitive interviews

The survey was open for 6 weeks in early 2016. One thousand one hundred and twelve people and organisations participated in the survey. The majority were healthcare professionals (89%), with responses from 97 members of the public (9%). Other responses were received from professional bodies and healthcare organisations. Participant characteristics are presented in supplementary tables 2-5. Eighty nine percent of respondents liked the concept of an ECTP, and 70% (n=307) of those who expressed an opinion about it were either satisfied or very satisfied with the prototype ECTP form. The thematic analysis of the free text answers are presented in table 1 and supplementary table 8. Data saturation was reached during coding before the themes were identified.

Clinicians understood the sections of the ECTP as intended and could complete or use it in an emergency situation. The subject matter was unfamiliar and complex for the patients interviewed highlighting the need for clinicians to be skilled in involving their patients in discussions and making sure they would be able to understand what was agreed and recorded on the form. No other issues emerged that had not already been raised in the survey feedback (see table 1).

[Insert table 1]

Transition from ECTP to ReSPECT

Phase 1 and 2 findings were used to develop the next iteration of the ECTP form and supporting materials. Key changes that were introduced are summarised in Figure 3.

The resulting new iteration used the new name: Recommended Summary Plan for Emergency Care and Treatment (ReSPECT). This new acronym emphasised that patients and their clinicians should respect each other's roles and contributions to the ReSPECT process.

Patient and public workshop

Eleven participants attended the patient-and-public-involvement (PPI) workshop. Participants reported a disconnect between the poster, which they felt advertised a *patient-driven* process, and the ReSPECT form, which was to be completed by *clinicians* during or following a dialogue with a patient. They highlighted that the messaging needed to clearly convey the importance of the conversation between patient and clinician and the importance of the patient making their wishes known. Suggestions were made that resources (e.g. a ReSPECT website) should include what sort of treatments are considered emergency treatments, and more advice for patients.

Phase 3 Usability testing

Twenty-nine clinicians participated in the 5 focus groups: 14 doctors (7 consultants, 7 trainees) and 15 clinical nurse specialists (palliative care and acute medicine).

Table 2 outlines the findings. More detail is provided in supplementary table 9.

[insert table 2]

The recommendations based on the usability pilot findings were :

1. ReSPECT should be made available for adoption without further substantial changes
2. Educational materials should be supplemented with video simulations and examples of completed forms
3. More implementation and on-going audit and quality improvement activity was needed to enable the necessary culture change and change in practice. Information should be provided to support sites or regions with implementation.

These were agreed by the Working Group, which also sought and followed legal advice about mental capacity legislation, to ensure that the form and guidance adhered to capacity legislation in the 4 UK home nations.

Discussion

ReSPECT, a new approach to emergency care and treatment plans was developed through a combination of synthesising knowledge from existing research and national expertise, and embedding evaluation with each iteration. Changes were made following a consultation, cognitive interviews, workshops and usability testing. The result was an approach which could be used for all age groups, in all health and care settings that was acceptable to both patients and clinicians.

Stakeholder participation was integral to this work. Its value is increasingly recognised for successful implementation.[28] Groups which successfully produce products need to be engaged; to come to wise decisions they need to have certain qualities[26] including diversity of opinion and independence. The ReSPECT Working Group had diverse backgrounds, roles and responsibilities. Members were able to draw on their specialist knowledge and from their personal experience to achieve the quality of 'decentralisation': when individuals do not have to conform to a controlling hierarchical bureaucracy. The sharing of power among members of the public, clinicians and health and care organisations led to what is defined by Goodman and Thompson as engaged participation;[16] the willingness for prolonged collaboration with clear objectives contributed to the success of the project.[25] Through structured processes of discussion, disagreement, and resolution of disagreement the Working Group formed collective decisions from individual members' own judgements; Surowiecki[26] calls this quality aggregation. By creating space for opposing ideas to be aired and the complexities of different health and care specialities and settings to be considered, new solutions were developed.[27]

The usability pilot demonstrated that ReSPECT was acceptable to, and usable by, frontline clinicians with their patients. Developing it resulted in a sense of shared ownership, and incorporation into ReSPECT of a wide range of "knowledge, knowhow and experience". These are characteristics identified by Mets and Boas as contributing to successful development of useable interventions.[28] The ReSPECT process will continue to be iteratively improved, in response to feedback from users.

The Working Group has made ReSPECT available to adopt by health and care communities and developed supporting educational and implementation materials. The Resuscitation Council UK will manage a process for supporting sites to adopt the ReSPECT process and for gaining feedback to

monitoring its use and its impact. Communities and organisations adopting ReSPECT have been asked to agree to certain 'rights and responsibilities', including a commitment to report adverse events associated with the use of the ReSPECT process. The NIHR has funded a mixed-methods evaluation of early adopting acute NHS hospitals.[29] An evaluation of ReSPECT's use in community settings is being planned. These national monitoring and evaluation initiatives, in addition to monitoring through local audit, should provide the opportunity to understand the impact of the ReSPECT process, including identification of any unintended consequences. It will also support ongoing development and sustained and effective use of the ReSPECT process.

Limitations

The results of the consultation survey are limited to views of those who chose to take part, and may have been biased towards those with strong views of support or opposition, and towards health professionals. This may account for why 89% had a favourable opinion of the idea of an ECTP. However, no new ideas or concerns emerged before all comments had been collated, suggesting that a good variety of positive and negative views were expressed. The qualitative analysis of the written survey answers and interviews meant that a breadth of views was represented, rather than only majority views. The sample size for the cognitive interviews was limited by resource availability, with only 2 participants from each of the different groups or professions. However, when the concerns identified by participants were compared to those raised by survey respondents the interviews contributed no new concerns. The small scale of the usability pilot means that some difficulties with the usability of ReSPECT may not have been identified. Feedback from GPs was limited. The pilot was not designed to evaluate the impact of ReSPECT on patient care and outcomes and was limited to testing whether clinicians in different settings could use the ReSPECT process and associated documents. The small scale of the pilot did not allow for testing in organisations in all 4 UK countries. Although the NHS operates in all four countries it is possible cultural differences that could influence responses to ReSPECT were not captured. Ongoing monitoring and robust evaluation of its use and impacts are needed as ReSPECT is adopted more widely. Finally there is a need to evaluate how ReSPECT, which provides a succinct summary relating to emergency treatments integrates with more detailed advanced care plans.

Conclusions

ReSPECT is designed to prompt and facilitate discussions about patient preferences to inform emergency care and treatment plans (including but not restricted to a recommendation about CPR) for use across all health and care settings.

This evaluation confirmed that ReSPECT was understood and could be used by clinicians and patients in a variety of settings. Having a single form that can be used for all patients in all settings means an important aim of ReSPECT has been achieved: it has the potential to improve communication between organisations. Further research will be needed to assess the influence of ReSPECT on person-centred discussions and decisions, care experience and on health outcomes.

Conflicts of Interest

Gavin Perkins' and Claire Hawkes' employer, the University of Warwick, received funding from the Resuscitation Council UK to conduct the evaluation. Professors Richardson and Perkins are National Institute for Health Research (NIHR) Senior Investigators. Professor Perkins is an Editor of Resuscitation. All authors contributed to the development of ReSPECT.

The development of ReSPECT was funded by the Resuscitation Council UK, with some contribution from the Royal College of Nursing. AR's contribution to the evaluation was facilitated through funding from the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care (NIHR CLAHRC) Wessex. Funders had no role in study design, data collection and analysis, decision to publish or preparation of the manuscript. The views expressed in this article are those of the author(s) and not necessarily those of the Resuscitation Council UK, the Royal College of Nursing, the NHS, the NIHR, or the Department of Health.

GDP, CH, ZF, AR, SA, DP, JS were members of the ReSPECT Working Group.

Data statement

All available data are presented in the article and suplementary tables.

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